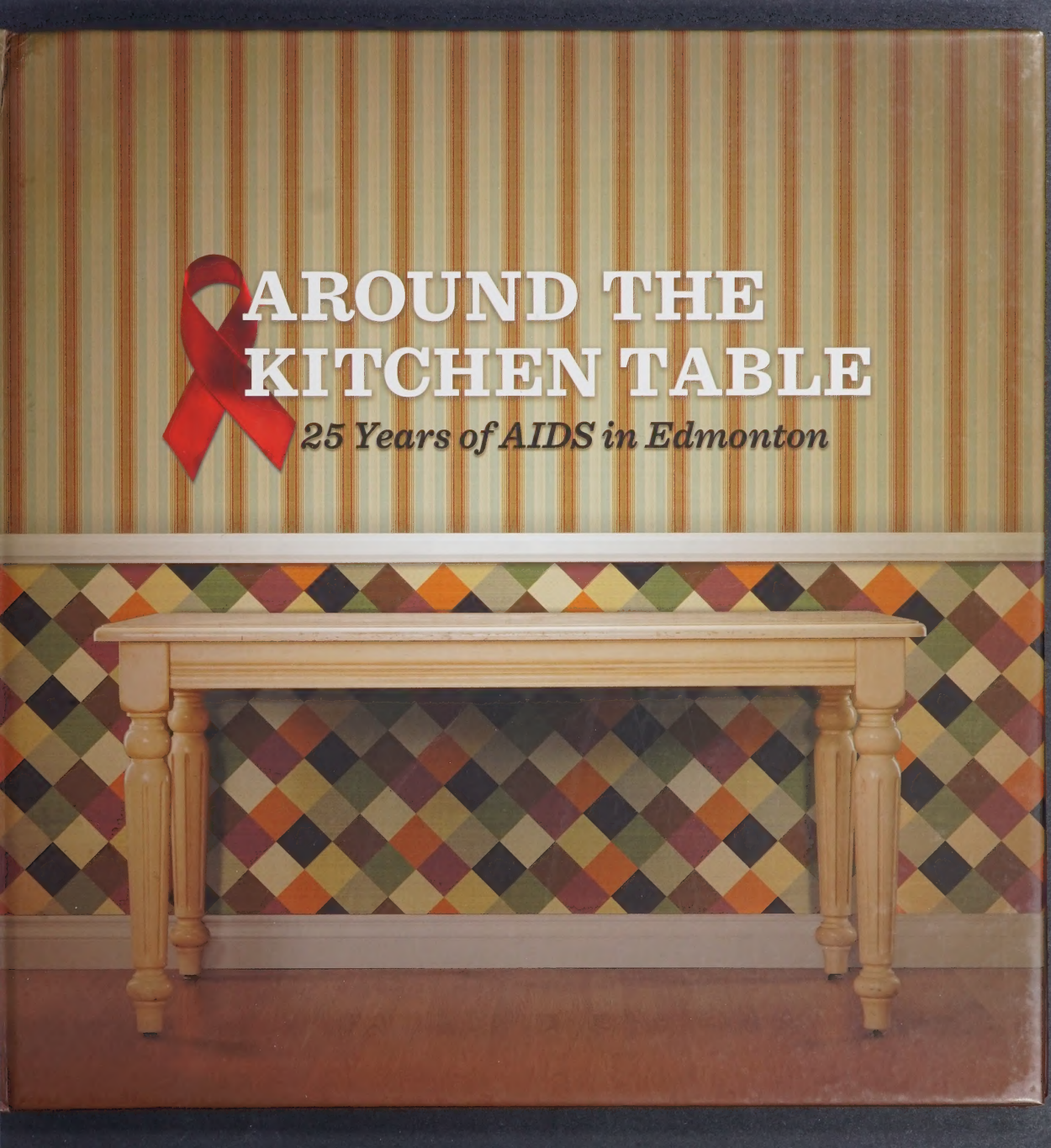

AROUND THE
KITCHEN TABLE
25 Years of AIDS in Edmonton

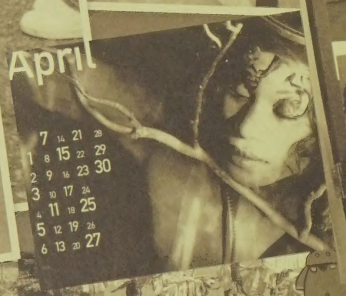

positive
women










April




HIV
EDMONTON





For everyone that has been a part of Edmonton's
HIV and AIDS movement in the last 25 years...
This book is merely a sampling of the people
that have given their hearts and souls to this work.



Five of us gathered around my table to figure out how to deal with AIDS locally...

MICHAEL PHAIR

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AROUND THE KITCHEN TABLE

25 Years of AIDS in Edmonton

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FOREWORD

The first case of AIDS in Edmonton was confirmed on July 1, 1984. A day or two later, a group of five from the gay and lesbian community met as a committee of GATE (Gay Alliance Toward Equality), which grew into a non-profit society, the AIDS Network of Edmonton in 1985, or the Network, as it was called then. In 1999, the Network changed its name to HIV Network of Edmonton Society, or HIV Edmonton as it is more commonly known today.

Although identified in 1980 – 81 in the United States, it was not until 1984 that the cause was found to be a retro-virus. There was no known medical prevention and no cure for AIDS, so the only treatment that could be undertaken was for the presenting illnesses, like pneumonia and tuberculosis. The progress of AIDS was extremely debilitating, painful, and led to death — usually in less than two years. For gay men and others, it was a terrifying time. There was a great deal of public fright and hysteria as AIDS was associated with three societal (and political) taboos — death, sexual activity and homosexuality. In retrospect, establishing a non-profit community group was a pretty brave and risky venture — yet it happened. Subsequently, the Edmonton community actively and aggressively responded to AIDS, then and now.

Having had an opportunity in the early 1980's to witness both the impact and the response to AIDS (then called GRID — Gay Related Immune Deficiency) across North America, I understood that it was imperative for the local gay and lesbian community to take the initiative to ensure prevention, education, and health services were adequately provided.

Venturing into a relatively unknown area, our AIDS work in Edmonton in the mid-eighties shaped a significant number of goals that I think have guided HIV Edmonton over its 25 year history.

I left Edmonton in August of 1983 for a year of study at San Francisco State University, sharing an apartment with a roommate in San Francisco's Castro area. After one week, I attended my first AIDS funeral — a friend of my roommate's. The extent of AIDS, and the subsequent mobilization of the gay and lesbian community, was staggering. Not a day went by without information, news, or rallies/events about AIDS. My return to Edmonton in the last days of June 1984 was followed by the first AIDS patient ("victim" in 1984), announced publicly on July 1. Five of us gathered around my table to figure out how to deal with AIDS locally. Out of that meeting, we adopted a name for our group that included the word Network. We felt that the breadth of AIDS work — education, information, medical care, housing, personal care, and counseling — could only be successfully addressed if the entire Edmonton community and its resources responded and did its part. The gay and lesbian community would lead and advocate, but we knew that other major institutions and organizations needed to do their parts. I do think that one of the significant successes of the Network was the ability to galvanize both the AIDS affected community and the broader Edmonton community.

Jumping into AIDS work, our small group soon realized that providing AIDS information and educational materials to gay men was going to need money. In August of 1984, we kicked off the Network's first fundraiser — Alice's Tea Party in Victoria Park. A friend of mine had access through the public schools to a set of Alice in Wonderland costumes we could borrow. On a Sunday afternoon, Tweedle-dee, Tweedle-dum and the White Rabbit hosted high tea at Victoria Park, supplying tea, cucumber and cream cheese sandwiches, tarts, and games of croquet, and raised around $300! I, of course, was the Queen of Hearts. That September, the Court of the Wild Rose contributed $800 and a grant from the Clifford E. Lee Foundation of another $800 arrived. Our committee began the search to rent an office for the AIDS Network of Edmonton. Funding had come from, and would continue to come from, a variety of sources.

Ross Armstrong was the first Edmontonian publicly identified with AIDS. Ross had come to Edmonton from eastern Canada some years earlier and was particularly known for and awarded medals for swimming. In his later teens, Ross was a member of the Canadian Olympic Swim Team and, after he moved to Edmonton, he participated as an Edmonton representative in the newly formed Gay Games. Shortly after being released from the hospital in August 1984, Ross became a part of the Network's team, becoming the face of AIDS in Edmonton. He attended and spoke at numerous local and national events. Often times, Ross was quoted in the media because he was the local person living with AIDS. In 1985, the Network named their office after him. He was in and out of the hospital with pneumonia and "wasting disease." Ross died on July 1, 1986 — two years after his diagnosis. Because so many of us knew him and thought of him as one of us, and frightening though it was to witness his fight with the disease, the challenges and suffering Ross endured and the courage he displayed during those first years of AIDS in Edmonton gave the gay and lesbian community, including myself and others, the strength and resolve to respond to HIV then — and for twenty-five years.

From 1985 to 2010, much AIDS work in Edmonton has been done — and much more work lies ahead.

MICHAEL PHAIR



01

The Founders and Early Days

FOUNDER PROFILES

MICHAEL PHAIR

July 1, 1984 — the first person in Edmonton with AIDS was diagnosed. I returned in late June from a year of studies at San Francisco State University where I had witnessed the incessant news stories, the deaths and daily funerals.

I knew the devastation to and the heroic responses of San Francisco's gay community to AIDS.

A couple of calls led to a meeting with 5 of us, and by July 4, the AIDS Network of Edmonton Committee was born.

Edmonton's gay community had to take the initiative in dealing with AIDS and I wanted to be part of that effort.

DR. COLIN SOSKOLNE

As an epidemiologist, I was concerned with how HIV was transmitted and finding out how to contain the epidemic. It was essential to work with affected communities.

I'd come to Edmonton from Toronto, where the relative numbers of people with HIV/AIDS was higher. I felt that this was an especially opportune time to intervene with public education to ensure that Edmonton experienced less of an AIDS burden than in the larger centres in Canada and the world.

It was a pleasure to engage with Michael Phair, with me serving as the scientist, and with Michael serving as the community activist on radio, TV and in the media in efforts to inform and direct public policy.



LIZ MASSIAH

I come from a long line of women and men who believe in fairness and demand respect for all. I've always been an advocate and 25 years ago, I was newly graduated with a Masters of Social Work and very involved in the lesbian community. Many of the important people in my life were gay men and hearing the insults and stigmatizing of them was infuriating.

Although we did not agree at the time, Michael and others now see value in the social work perspective of strongly advocating, insisting, demanding, and being a pain in the neck for others with expertise to get involved in a strong positive way.

After all, the original name included the word "Network", suggesting an important paradigm linguistically. We can be part of the issue, but it's not all up to us. We had to start the work since only those impacted can ever really create change. It is the only approach that ever works.

It is important to walk the talk, not just talk it — so we did and still do every day.



TOM GALE

Coming to Edmonton in the early 1980's, there weren't a whole lot of out gay people. I was out and my partner was out. And the AIDS scare hit. Then it was as simple as knowing we had to do something. We plunged in with both feet and the heck with the fear.

I thought it was going to be a whole lot worse because it seemed there were just huge amounts of people being infected. I realized we'd have to do our part in Edmonton too. I knew there were a lot of gay men in Edmonton who were traveling and could get infected and sure enough, it happened.

There were so many brave people everywhere — in a case of great need, there will always be someone who steps up.

And Michael Phair stepped up. You have to give him credit for being a great leader and not self-aggrandizing. Everyone just did their job. I guess we all took that from working with Michael. It was a time I never hope to see again, but it was also a time of great togetherness and helping one another. And that's something worth recognizing.

**photo unavailable*

DR. JERRY KATZ

I was one of the first doctors to treat AIDS patients. The new "gay plague" came in 1983. By the 90's, I had 265 AIDS patients. I really felt that this was their holocaust and I didn't want to stand by and let this happen.

When you try to change human behaviour, it's very hard. Sometimes the people you try to help mistrust you. I was even attacked by a gay man for fear mongering and being antigay.

There was a very small group of individuals who were committed to help. It was very rewarding to see how people pulled together at the AIDS Network of Edmonton.

The intense trust that these people had in us created an onus to try extremely hard. It was an amazing time and the responsibility in the early days was very difficult.

I look back and marvel how we got through it, but many didn't. I remember the day I got the call from the hospital, the day the 40th patient died. I sat at my desk and cried. There are people who can turn it off, but I could not. I developed very close relationships with many of these individuals and they were like members of my family who were all dying.

I look back on this bittersweet situation and major event in history and I am grateful I was there to help.

DR. LORNE TYRRELL

I recall the early days of the appearance of HIV in Edmonton. Originally, there was no specific treatment for the virus, only the opportunistic infections. Early treatment was not very effective and most patients died within 1 or 2 years of diagnosis. This all changed rather dramatically in 1996 with the introduction of protease inhibitors and the beginning of HAART. Today, life expectancies are near normal. What a dramatic change and what an achievement for discovery research that led to the development of new therapies and to careful clinical trials that transformed the disease.



DR. BARBARA ROMANOWSKI

I remember the night we sat around Michael Phair's kitchen table. I even remember the menu... spaghetti, I believe.

We got to know each other through individuals who were infected. Some at the table were active in the gay community. And if you're the physician providing care like I was, your paths just cross.

We committed to help these people together and I hope have provided care, support and education.



CHARLES BIDWELL

As a gay man, this "plague" was killing my friends and could kill me next.

We had no idea of how it was spread and there seemed to be no interest in the wider community to research the cause, or provide support for those who were the first "victims."

Actually, some of the first and best caregivers outside the health professions were our lesbian friends, who seemed to be immune.

There was certainly a selfish or self-interest component to my wanting to support the Network, because I felt that I was as much at risk of needing their resources as the next guy.

Margaret Mead, the anthropologist, said, "Never doubt that a small group of thoughtful citizens can change the world. Indeed, it is the only thing that ever has." Michael Phair and the others he gathered around his kitchen table certainly proved that point in Edmonton.


VAL GERVAIS
Former HIV Edmonton staff member
OSS / HOPE



MICKEY WILSON

Former Interfaith HIV/AIDS Program Executive Director



02

The Doctors and Healthcare Providers



DR. STAN HOUSTON

Director Northern Alberta HIV Clinic/
Former HIV Edmonton Board Member

I'm the eldest of three siblings who all chose to enter the medical profession. Just before I went to medical school at the University of Saskatchewan, I met the woman who would become my wife. The University had an elective that allowed me to go to the Democratic Republic of Congo in Zaire. That trip changed my life.

I graduated in 1975 and took a tropical medicine course in Liverpool, UK. From there, it was back to rural Africa, to a little country called Lesotho. The country is geographically surrounded by South Africa, but has always been independent. While my wife and I were there, our son was born. At the time, Lesotho had people dealing with tuberculosis and sexually transmitted diseases. When HIV came along, we could see that Africa was fertile for it. I had no concept then, however, of how my time in Africa might be relevant now.

When we returned to Canada, I started my training to specialize in infectious diseases. Edmonton had some very strong post-graduate programs that my wife and I both wanted to take. So, Edmonton it was. During this training, we saw the first cases of AIDS. I don't think anyone thought it would be such a dominant thing. It was interesting, exciting, a little sad and a little scary, because we didn't know anything about how it was transmitted. The most memorable part of it for me was the stigma and fear associated with it, even in hospital and amongst health professionals. We aren't uniquely gifted with being rational. There was so much we didn't know.

I think I saw a handful of people with HIV during my fellowship and it was all gay men. But then it showed up in Africa. It is a very special place to me, so we went back, this time to Zimbabwe. We were there for three years at the university and we had a daughter during that time. HIV hit the country right around the time we arrived in 1987. Then it exploded. That, again, was certainly interesting and exciting.

We were always learning new things. It was, however, even more devastating and tragic. No one had anti-retroviral drugs then. The main thing we could do was diagnose people and treat infections as they came.



I came back to Edmonton in 1990 and have remained here. I started with HIV Edmonton as the Director of the Northern Alberta HIV Program. I spent four years on the board of HIV Edmonton as well. In those days, gay men were the overwhelming focus of the epidemic.

In the early 1990's, we saw the disease take off in intravenous drug users in the aboriginal community. Having worked in Africa and early on in a northern aboriginal community, it was obvious the aboriginal community was at high risk. It's disheartening that we can't be more proactive in terms of effective, imaginative, and energetic solutions; sometimes it feels like Alberta hasn't even tried. I feel profound disappointment in the fact that we lag behind the rest of the world in proactive initiatives. We are even behind Zimbabwe. Alberta really dropped the ball on this one.

HIV is the most important infectious disease, one that was universally fatal. We applied the knowledge as it emerged, which was pretty fast. Then, a few short years later, we came up with a treatment. It was exciting to live through that time. Alberta did commit from the beginning to pay for anti-retroviral drugs and they generously funded staff to run a program to deliver HIV care. So, we had this really fantastic group of people — nurses, social workers, psychologists, and pharmacists who met the extra complex needs of patients and made new treatments their priority.

It is rewarding to see, not only the advances of the new drugs, but also patients making strides in all aspects of their lives. There were Lazarus-like recoveries for many patients. Over a very short period of time, the whole picture changed from being palliative care doctors to treating a chronic illness, with the hope of normal health and a full life.

HIV Edmonton constantly rethought their role and how their services should evolve. That was fundamental to their ability to serve the community.

I would most like to see reduced incidence and transmissions in Edmonton. We can't have very much of an impact on that, because we don't have much to say in terms of public health policy. I do not, however, have any plans to step back any time soon. You see these changes and it's rewarding to have played a small part in them. Working together with other agencies in Edmonton, I would like to see a model of the highest quality scientific care, along with really sensitive care for people from a wide variety of backgrounds. To see that continue and strengthen, that would be my aspiration.

SUSAN JAMIESON

Edmonton STI Clinic Educator,
Former HIV Edmonton
Board Member




BERNIE MODROVSKY
Northern Alberta Clinic:
Social Worker
TED BIRSE
Northern Alberta Clinic:
Nurse Practitioner



DR. BARBARA ROMANOWSKI

I've spent my entire adult life here in Edmonton. After completing my infectious disease fellowship, I had a job offer from the government to run what was then called the Social Hygiene Project. It's now called the Sexually Transmitted Disease Program. At first, I figured hey, it's a job; I need a job. I'll do it for a year. Then I fell in love with it, and developed this sub-specialty in sexually transmitted infections. That was in 1979, before HIV.

I think I've always been drawn to the disadvantaged patient — by virtue of lifestyle, history, life experiences, or disadvantaged in terms of physicians not wanting to deal with individuals because they had diseases they believed had no significant consequences. This was the first time in Canada where someone with an infectious disease background was getting into that area, and that person was me. I was the sole individual providing these people with care in Edmonton.

It was taxing and frustrating because the care was palliative in the early days. We didn't have the ability to treat the underlying problem. Many of my patients died with dignity, as they wished. Back then though, there was a lot of fear. I spent an inordinate amount of time doing public awareness, because people heard the word AIDS and they ran. People with HIV/AIDS couldn't get medical care, their GP's didn't want to see them, and they were denied dental care. There were no social services programs. It was very difficult for everyone. Families or partners often abandoned them. When they died, the regulations were such that their coffins had to have a metal lining. That's how little was known about the virus. We journeyed on together, however, and by the time we sat down around Michael Phair's table, there was this realization that they needed much more than we were able to offer alone. We knew we all had to work together.

When I occasionally see the old lists of individuals, I can't even recall the number of funerals I attended. I did it for probably seven or eight years, but there were just too many. I had to take a step back. It was impossible to provide care plus go to their funerals. I found it just too emotionally difficult.



The gay community in those early days was superb at self-education. People educated their friends and came together to support each other through the AIDS Network, but also personally and privately. Now we're seeing a resurgence of new cases in young gay men. It's sad, because the mindset is that it's a disease belonging to the older guys, and the young guys don't think they need to be concerned about it. I think people are right when they say that the pendulum swings. Twenty-five years is not very long.

The positive news is that it is now considered a manageable, chronic disease. The negative is that, for some people, it makes the infection somewhat trivial. It's still a disease that can easily kill people if we don't pay attention to it. I believe it's going to continue to be a significant problem.

We all have our ways of dealing with work-related stress. I do it through literature, music, friends, and physical activity. However, sometimes you just can't get away from it. You often do take patients home with you, mentally and emotionally. We are no good to them if we are not solid on our own two feet. That doesn't mean you can't cry with your patients or hug them, but if you don't have your feet solidly on the ground, I don't believe you can do a very good job.

I've been working in this field for 25 years now. I really love what I do. I enjoy my patients. My research is not lab-based, but clinical, so unfortunately I'm not going to discover the drug that turns this virus off. I think all of us in the field can't wait for a cure. I wish I could say that I have so much free time because I've cured all my HIV patients and that I'm taking a very early retirement.

I hope I have educated patients and colleagues, and that I have provided compassionate care. I've certainly learned from my patients, and, for most of them, there has been mutual respect. They are patients, but they are individuals first.

I never expected to care for people who would die on a regular basis. That's not why I went into infectious disease. I chose to learn from it, however, and hopefully become a better physician at the end of the day.

That time was amazing — all of us in our tiny rowboat. It had no leaks and we learned to row together. It was all we needed. We were a group of individuals who were open-minded, not looking for the limelight, and no one trying to stake out their territory. We recognized the problem and the need to do something about it. We all did what we could and moved forward. The rowboat then became a motorboat, and, 25 years later, it turned into a great ship. It makes me proud to have been a part of it, and to continue to help navigate that ship.



DR. GHALIB AHMED

Physician who worked on HIV
Edmonton's methadone program



03 The Volunteers



TED KERR

Former HIV Edmonton Volunteer and Artist in Residence

HIV/AIDS impacts the entire world. It shows you more about global politics than anything else I can think of right now. I think of myself as a global citizen so that was one of the major reasons I started volunteering with HIV Edmonton in 2004. I also wanted to get in touch with my gay heritage and contemporary gay issues and I wasn't finding that in any other way. I wanted to meet other gay people outside of a bar setting, so HIV Edmonton made the perfect sense to me.

I got to HIV Edmonton and there were no gay people to be found.

I didn't understand why there weren't a lot of gay people and why there was a hesitation to interact with me. Then I understood that there was this history. I realized I had an opportunity as their first artist-in-residence to re-engage gay men. So, I used my time there to focus on gay men's health and start the dialogue.

I did a postcard project. One of the cards reads: "Online everyone has a swimmer's body." It's kind of poking fun at the idea that people lie, so let's take care of ourselves and be proactive. It was also a wink to the idea that, in Edmonton, there are not a lot of spaces for dudes to meet, so a lot of the time they meet online. As HIV Edmonton began to shift their focus on the needs of injection drug users, a bit of a disconnect began to happen with the Edmonton gay community. As a result of this rift, the gay guys weren't going there to talk about HIV. They were talking about it independently or maybe not at all, so bringing them back to HIV Edmonton is one thing I've done.

Now, if you come to events or see the people in the office, it's much more diverse. It's a cross-section of the people affected and infected with HIV/AIDS. It's been really beautiful.

I still think there is stigma and discrimination around HIV. But if you look at who accesses HIV Edmonton, it's the people who have to. If you have decent medical coverage, you don't ever have to access HIV Edmonton; you can just go to your doctor to get your AIDS meds. You may never outwardly appear ill and because the medication is better and it's not as complicated as it used to be, you can live your HIV privately.



HIV Edmonton has made me. Without my relationship with HIV Edmonton, I wouldn't be the person I am today.

That's kudos to the people who came before me and did amazing work. But it further stigmatizes the people who need to access services like HIV Edmonton.

We wanted to create an AIDS-aware community so people were a part of us, not because they had to be, but because they wanted to be. They aren't living with HIV in their body, but they still live with it in our culture. And that impacts everything else, so it's in our best interest to be interested in HIV.

If I was to put a success behind anything I've done with HIV Edmonton, it would be that we've realigned gay consciousness and HIV consciousness. I think its super important because HIV had a huge impact on the gay community. It was devastating, but also in some ways, really positive. What we should be doing now is looking at how we reduce the harm and how we move forward in triumph. I think as an AIDS service organization, HIV Edmonton has a duty to all people.

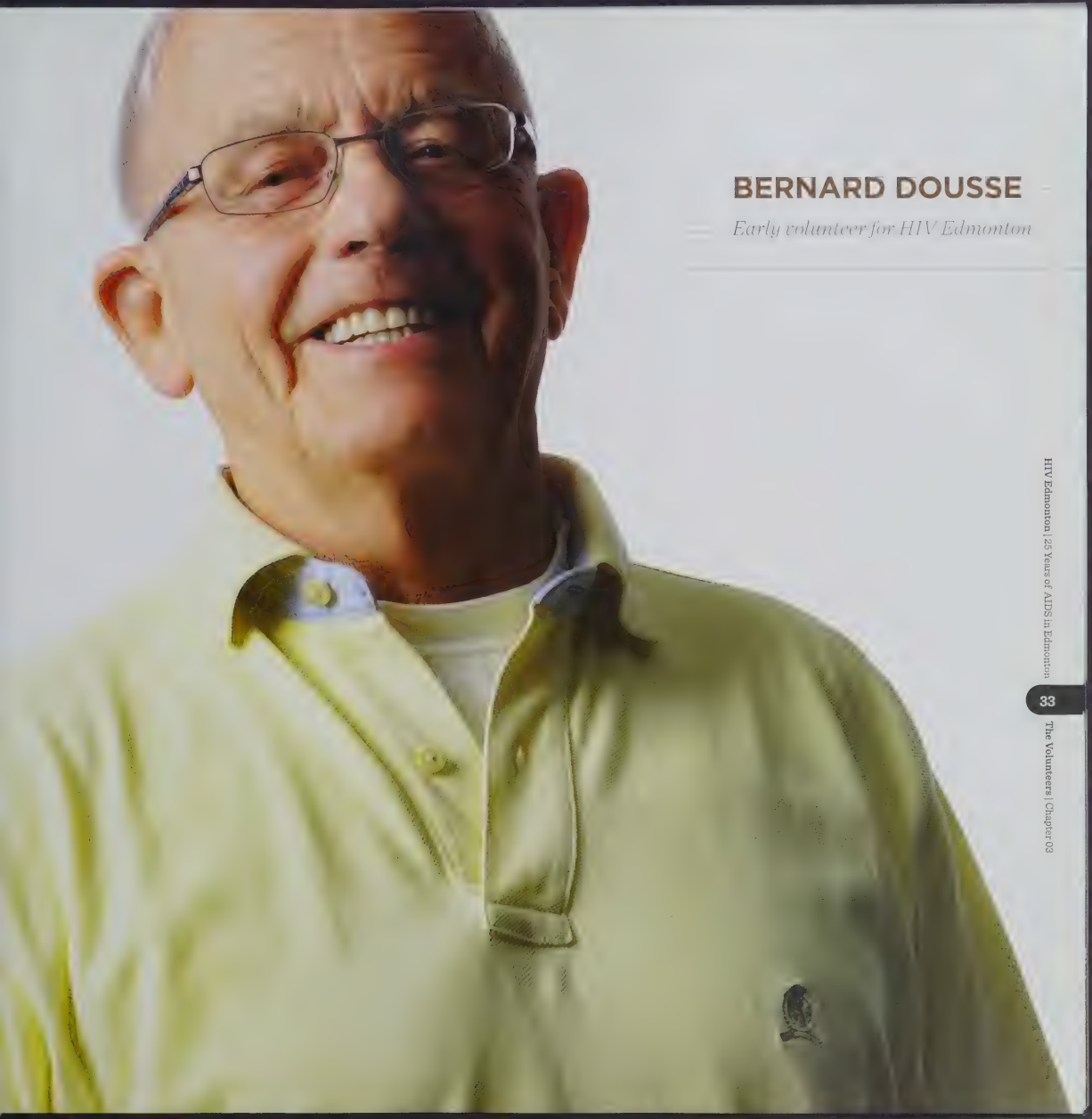
HIV Edmonton has made me. Without my relationship with HIV Edmonton, I wouldn't be the person I am today. I wouldn't be as knowledgeable as I am about certain things. I wouldn't be as compassionate. And I don't say these things to brag. Because I don't think we own our genius or our skills or compassion... it's something that moves through us. I'm just acknowledging what moves through me.

When I look at what I represent as a younger and engaged voice, a voice that is part of other conversations... I'm proud to be a placeholder.

The horror of HIV/AIDS created the response in the early days. It created community and made the whole rainbow of gay people work together because no one else was helping them. It's a lesson I don't fully grasp yet, because it's so overwhelming. But I think it's a lesson that we need to keep teaching ourselves. Everything that happened at the beginning of the crisis is coming alive today in gay people who are artists and hipsters. The poly-sexual kind of youth taking on the lessons from the early AIDS crisis is something that blows my mind. It's amazing.

I have a sense of my role and I'm happy to be one person beating my drum as solidly as I can. I'm overjoyed to hear those who drums have a different beat than mine, and the other drums working in concert with me.


TRUDIE MACLAREN
HIV Edmonton archivist for 18 years



BERNARD DOUSSE

Early volunteer for HIV Edmonton



LYLE WATLING

Former HIV Edmonton board member, longtime local and national volunteer



04 The Leaders



SHERRY MCKIBBEN

Former HIV Edmonton Executive Director

There is no way you can work in the field of HIV without being affected, because you come to know and love people — and then they die. I grew up right here in Wabamun, Alberta. My father was a coal miner. Eventually the bottom fell out of coal mining, so he became a masseur. We moved to Edmonton, where I spent the second half of my childhood with my sister. She's my best friend. We're six years apart, so from different generations. She followed the standard pattern of marriage and children. She quit her job and eventually became a librarian later on.

I came of age in the early 60's, just as the hippie movement was starting. So there was a lot of sex, drugs and rock n' roll. I actually did get married, but it didn't last. I ended up in social work by accident. I graduated from university with a Bachelor of Arts, which is what you got in those days. I had been in nursing and didn't like it, because it was too hierarchical and rigid. I fell into social work and I loved it. It's been a fantastic career for me. I like the fact that I engage with people and that I am able to be of assistance to them. It fits with my philosophy of treading softly upon the world and trying to leave it a better place than the one you entered. It has provided enormous opportunities and challenges, some good and some bad.

In the mid 90's, I worked with the Norwood Health and Family Centre. I'm a lesbian in a lesbian relationship and I experienced quite a bit of discrimination there. Then a job came up at HIV Edmonton and I became Executive Director on June 1, 1998. The organization was still predominantly gay at that time, but the people who were getting the disease had shifted. The year 1998 was the very beginning of the real impact of the HIV treatments. Up until that time, there was a pretty steady stream of deaths. Then they started dropping off.

There was a group of volunteers, mostly gay men, and some women too, who had been trained to be caregivers for people who were dying. They were really mad that I wasn't giving them any business. Here were people



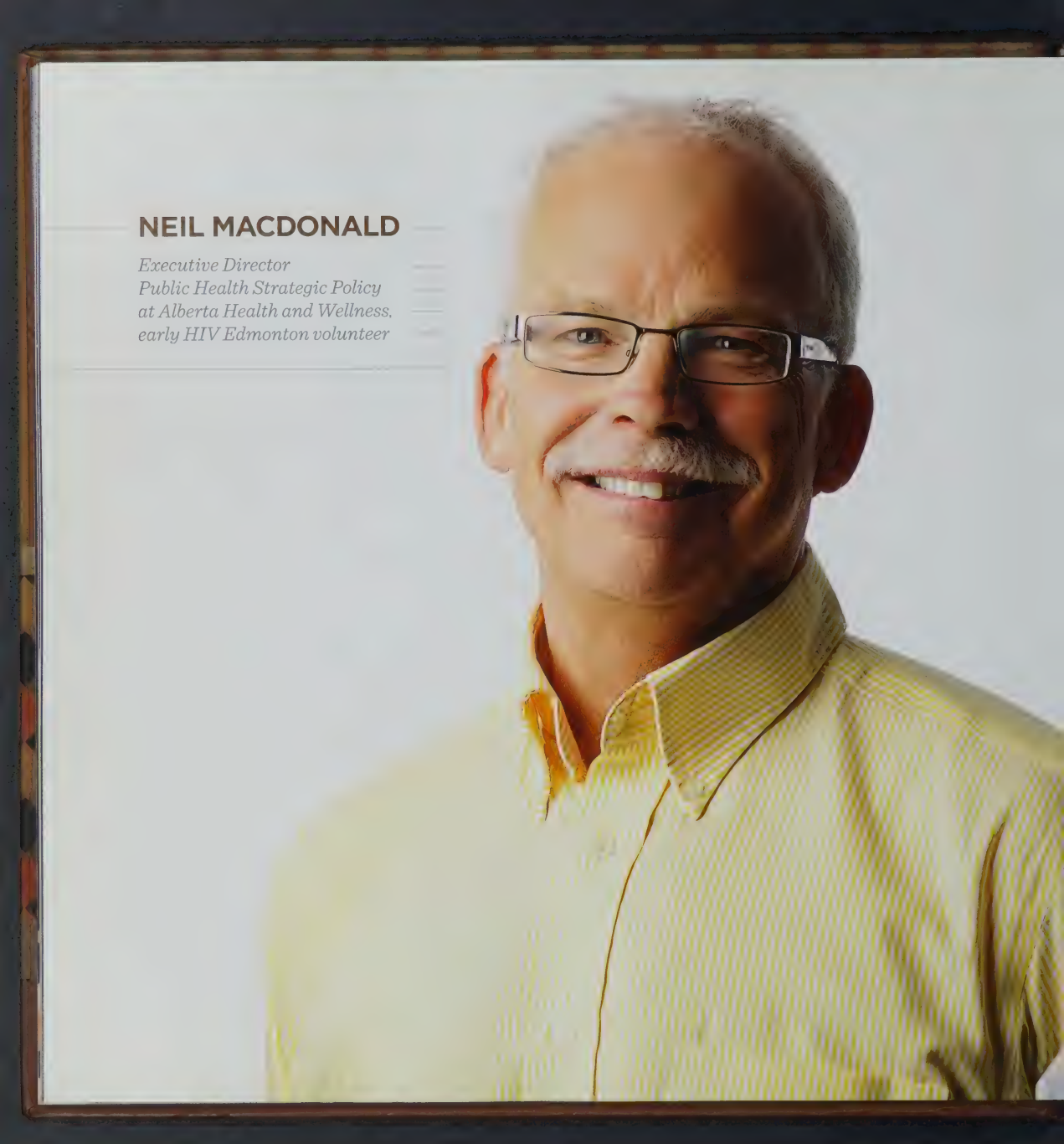
who had really dedicated themselves to assisting people who were dying, but people weren't dying anymore. We had to figure out how to become a different organization. People were living longer, so they had to learn to live. It also involved aboriginal street people and others who were economically disadvantaged. It was very difficult. Not just for HIV Edmonton, but for the whole AIDS movement in Canada.

Although the gay community is still present with HIV Edmonton, it was, nevertheless, very hard for them to give up their home. The AIDS movement was very tied into pride, and the two were synonymous in a real way. The AIDS Network was a place where some of that coalesced. To lose that momentum and organization was difficult, and there was certainly lots of anger. Some of it was directed at me. There was a lot of push back internally and externally. I'm no pushover and I moved forward because I had other people around me who also had strength, and who were supportive of that movement. I could not have done it without their assistance.

I was trying to create an organization that would be as open to all those impacted by HIV as possible. I think what was the most rewarding was to see people move from a place where they saw themselves as victims, to a place where they felt they had some control of their lives. It wasn't infrequent for people to say HIV gave them their lives back. I was there until 2006. Other organizations spawned from HIV Edmonton. It was good in that it created many different voices, but meant that turf warfare was exacerbated. The fights in the HIV world over turf were so fierce because it was new, and people were trying to stake out their ground. There were many dynamics, such as the politics of oppression. This is where you don't want anyone to get ahead of you. So as they are running down that hill, you grab their ankle and trip them. You see that in all oppressed communities, because they learn the techniques from their oppressors. They apply them to each other and it creates tension and difficulty, often with overlapping programs, which end up being less effective, in that they each end up with a smaller piece of the funding pie.

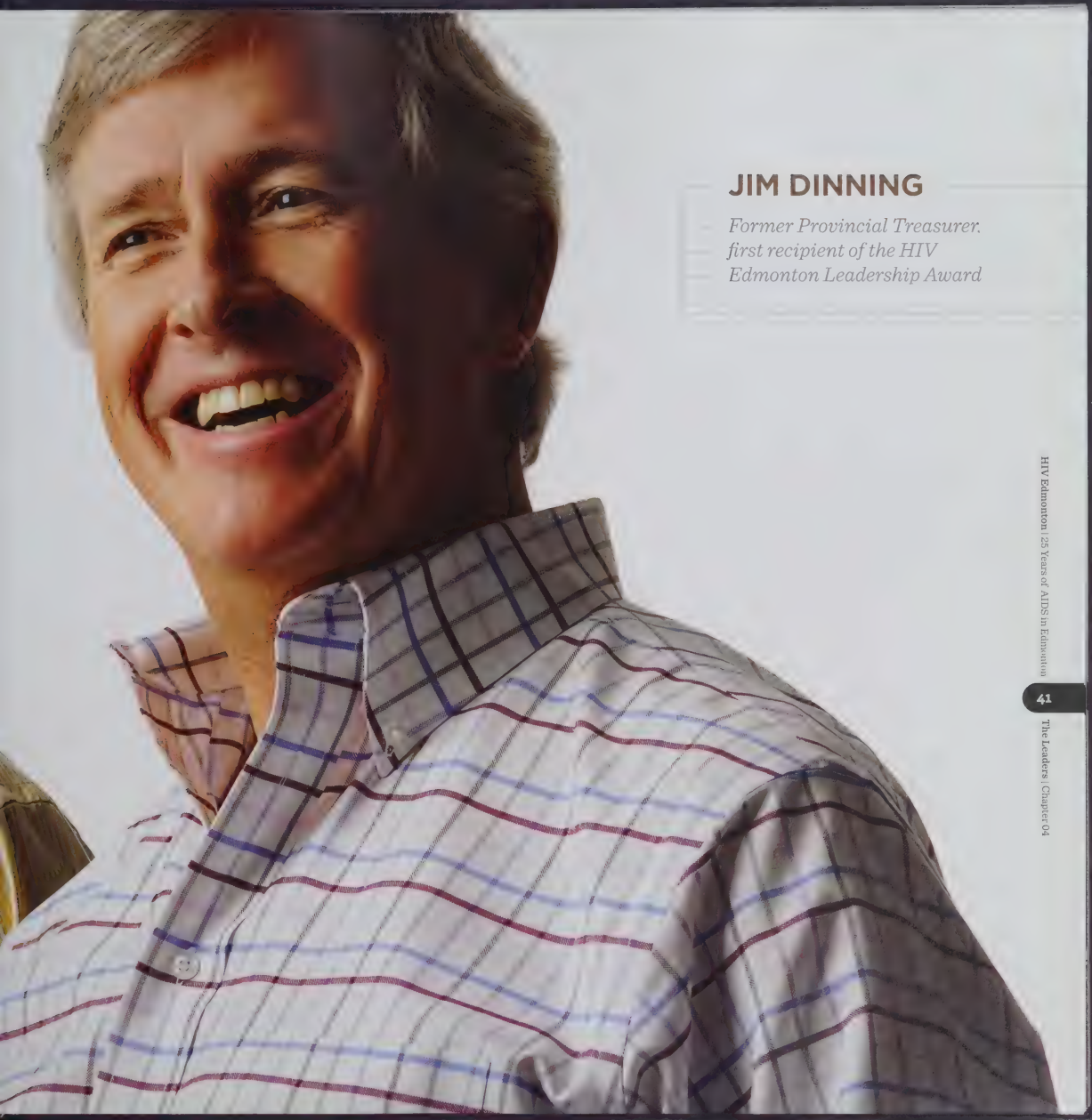
Working in the field of HIV changed me. The biggest way was helping me realize that I was going to have to keep learning for the rest of my life, in a way that I hadn't appreciated before. With HIV work, you have to be able to stop on a dime and change directions. If you stay in one spot and keep doing what you're doing, you're done, you're over, it's too late. That's the lesson I learned from HIV, which is true in life these days.

The most rewarding thing globally is seeing that HIV Edmonton remains successful. I'm over 65, so I'm working into retirement, but I plan to work as long as I can. To engage in my community and enjoy the retirement that social workers enjoy, which is to feel satisfaction in the work one has done. To be able to genuinely say, "I think I've accomplished some significant things in my life and I'm happy about that."



NEIL MACDONALD

Executive Director
Public Health Strategic Policy
at Alberta Health and Wellness,
early HIV Edmonton volunteer



JIM DINNING

Former Provincial Treasurer. first recipient of the HIV Edmonton Leadership Award

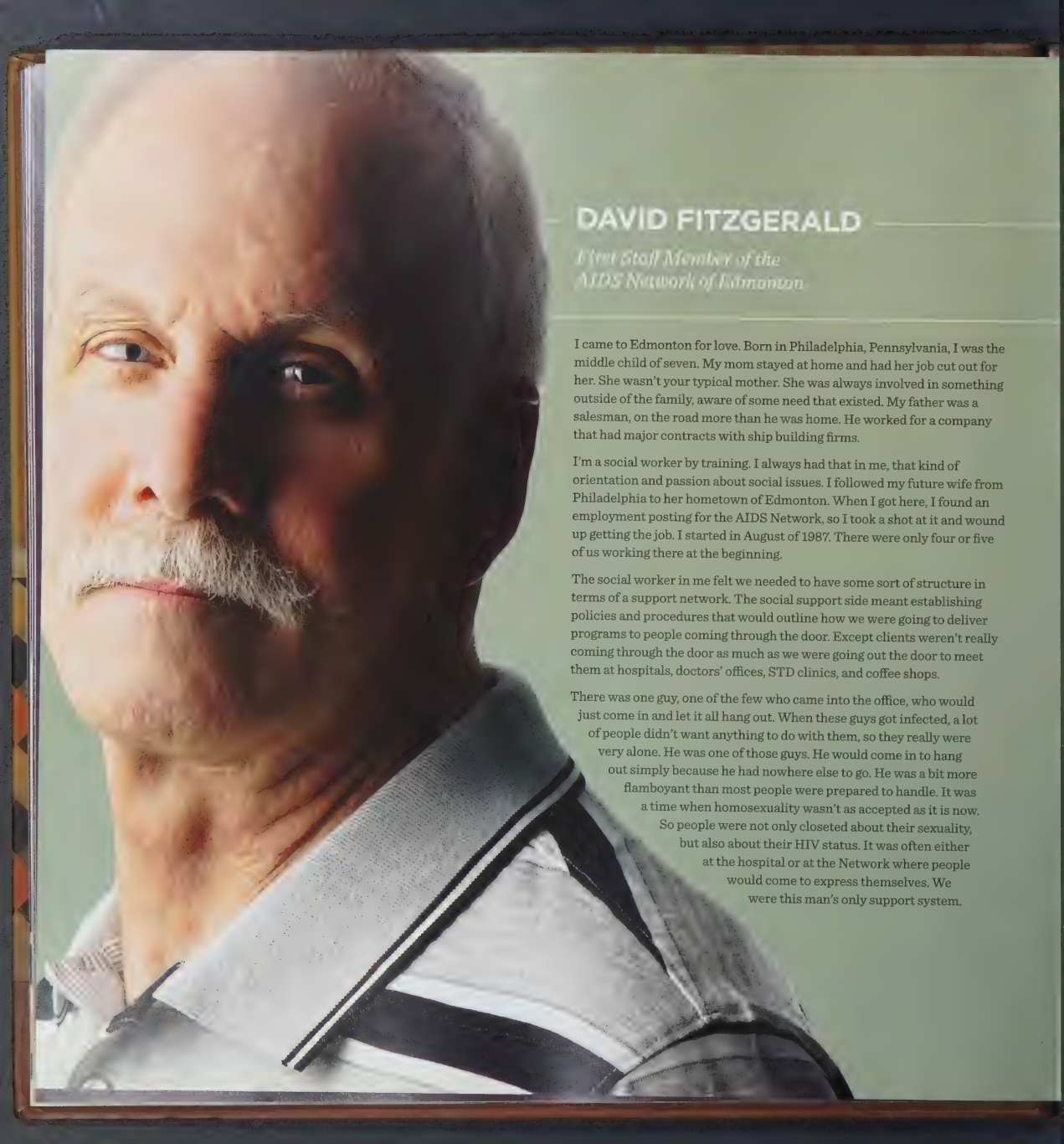

HONOURABLE
ANNE MCLELLAN
Former Minister of Health for
Canada, worked to help double
the AIDS Strategy





05

The HIV Edmonton Staff Through the Years



DAVID FITZGERALD

First Staff Member of the AIDS Network of Edmonton

I came to Edmonton for love. Born in Philadelphia, Pennsylvania, I was the middle child of seven. My mom stayed at home and had her job cut out for her. She wasn't your typical mother. She was always involved in something outside of the family, aware of some need that existed. My father was a salesman, on the road more than he was home. He worked for a company that had major contracts with ship building firms.

I'm a social worker by training. I always had that in me, that kind of orientation and passion about social issues. I followed my future wife from Philadelphia to her hometown of Edmonton. When I got here, I found an employment posting for the AIDS Network, so I took a shot at it and wound up getting the job. I started in August of 1987. There were only four or five of us working there at the beginning.

The social worker in me felt we needed to have some sort of structure in terms of a support network. The social support side meant establishing policies and procedures that would outline how we were going to deliver programs to people coming through the door. Except clients weren't really coming through the door as much as we were going out the door to meet them at hospitals, doctors' offices, STD clinics, and coffee shops.

There was one guy, one of the few who came into the office, who would just come in and let it all hang out. When these guys got infected, a lot of people didn't want anything to do with them, so they really were very alone. He was one of those guys. He would come in to hang out simply because he had nowhere else to go. He was a bit more flamboyant than most people were prepared to handle. It was a time when homosexuality wasn't as accepted as it is now. So people were not only closeted about their sexuality, but also about their HIV status. It was often either at the hospital or at the Network where people would come to express themselves. We were this man's only support system.



We gave, we got, and it changed us all for the better.

We were so focused on connecting with people and trying to provide some sort of cocoon or safety net that we weren't so focused on the fact that they were going to die. It was more about what can I do to help them through this process. When the deaths started occurring with regularity, we were all very passionate about ensuring that they had the best quality of life possible. Although their deaths did, of course, affect us, we knew we had done all we could. There was always someone else who needed us.

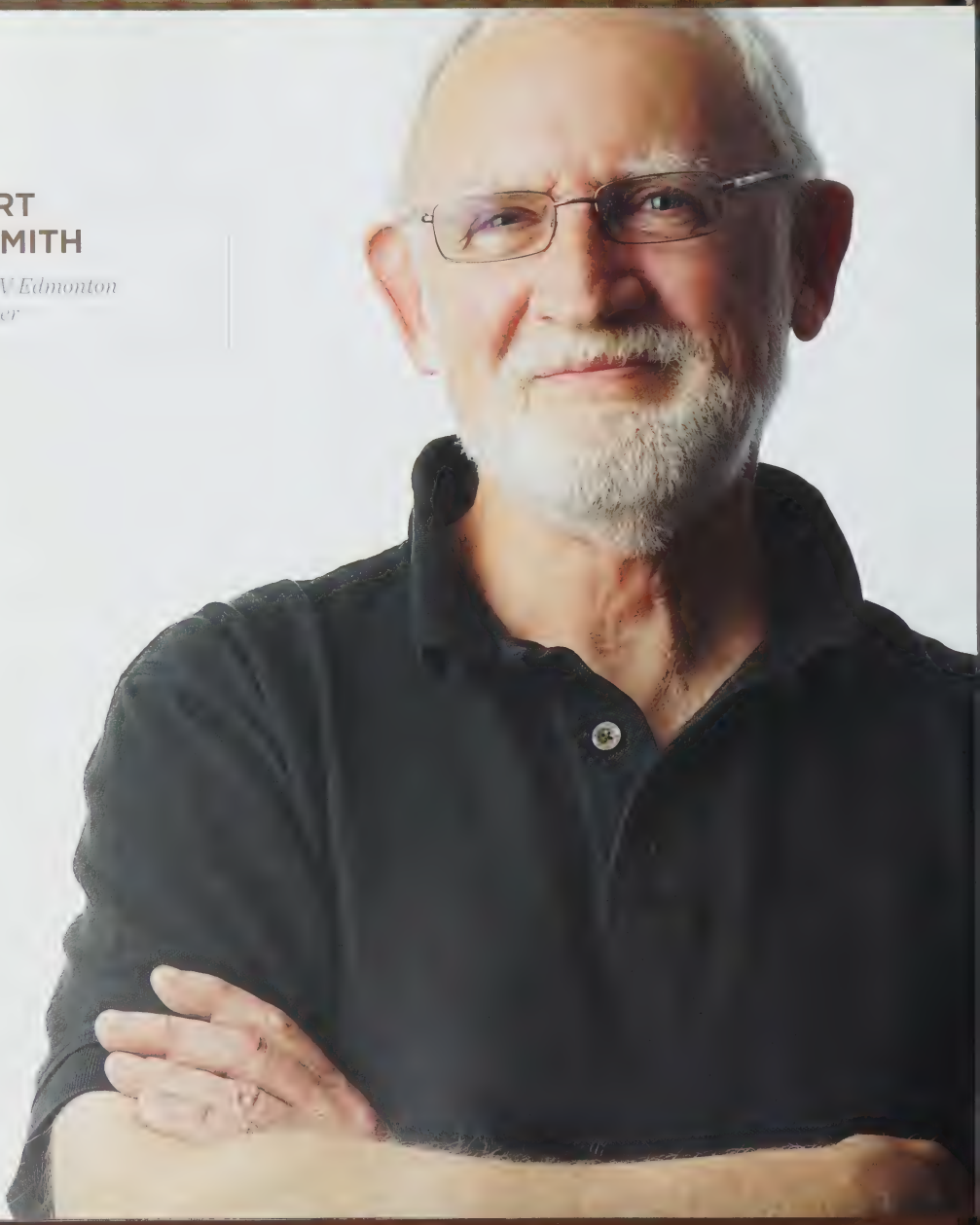
I was there for nine years, but the first four were very intense. I remember there being a real sense of urgency, knowing we had to do something. It was big. The Network became not just what you did from 9 to 5, five days a week, but it was what you did beyond that — the walks, the evening events — it became part of who you were. Maybe it's still that way. It had that ability to really engage you. I don't think anyone could have worked there then and not have been passionate about it.

What's interesting is the emotion that I still feel. When I reflect back on all of those early years and what we all went through together, having been a part of something from the ground up was really special. It changed me. I can't say how, exactly, but I know it did. I grew up in the sixties and seventies and had done a lot: working in the coalfields in Kentucky, working with homeless families in Philadelphia. Those experiences helped prepare me for my work with the Network, but I don't know if anything could have prepared me for the intensity of what we faced. As a result, I would guess that anyone who worked there figured that we gained more than we gave.

Up to a few months ago, I would have said that I had, indeed, gained more than I gave. But then I met up with a man that I knew in the early days at the Network. I was the first person with whom he had made contact. Twenty-five years later, he shared with me that he had always remembered what I had said to him that day; that I had changed his life with my words. I don't recall what I had said, but it had obviously been important and left an impression on him for all that time. I'm certain there were also many others who were able to feel better because of something we did. That man showed me the balance. We gave, we got, and it changed us all for the better.

ROBERT WM. SMITH

Former HIV Edmonton staff member





DAVID USHKO

Former HIV Edmonton board member, ongoing volunteer


KATE GUNN
Interim Executive Director
of HIV Edmonton 2001 – 2002



06

The Staff of Partner Organizations Through the Years



MAGGIE MCGINN

Former Executive Director, Living Positive

By the time I was 26 years old, I had lost a sister and two children. By the time I was 36, I was HIV positive. My parents had eleven children and I was smack dab in the middle. Out of seven brothers and three sisters, I was number five.

In 1974, I married my first husband, Jim, had my first child in 1975, and my second in 1976. Our daughter, Carrie, was severely handicapped with a degenerative brain disease and died when she was seven. My son, Andy, died during childbirth after I was in a motorcycle accident. Jim and I split up three years later. I remarried a couple of times and now I have Jessie, who is 28 years old, and Stephanie, who is 23.

As a single mom, I started upgrading because I'd never finished high school. At that time, I started looking into really dealing with my past. I knew if I were going to actually have a real life, I'd have to get through the depression. When you're in your twenties and you talk about dead kids, people always say "I'm so sorry for you" and then they don't want to talk about it again. I learned not to talk about it because people would disappear out of my life.

So, I was in this hospital program trying to deal with the death of my children and my depression, and decided I was going to go get an HIV test. At the time, I was renting a room to a nurse. She had this book called *AIDS: What Every Responsible Canadian Should Know*. It's a little orange and white book that I'll never forget. Knowing that I had never used condoms in my life and never used protection, I figured, what the hell, I'll get checked for everything — never thinking this could happen to me.

Two weeks later, the doctor took me into his office, sat me down, and handed me a manila file folder with the following written on it in big, black marker: "HIV POSITIVE, HIV POSITIVE." It was April 16, 1992, at 5-something in the evening.

I didn't know whether or not I could touch my kids. I was freaking about things like licking their ice cream cones and spitting on a Kleenex to wipe their faces. I was so afraid I'd already given it to them. I went to HIV Edmonton and got the girls' blood tests done. The results were back in four days and they were negative, so that was a relief. I therefore assumed I got it after the kids were born.



I was in a drug trial in Calgary and found out my second husband, Steve, had died in 1991 of AIDS. His mother hadn't bothered telling me because we had split up in 1986. He was diagnosed two years before me. Steve had been really sick, so I thought I didn't have very much longer to live. But at least I knew where I got the disease.

I connected with HIV Edmonton and became a part of a Health Canada project. From that, I went to the Canadian AIDS Society. We were trying to get people to form a coalition of HIV positive women, because there was no such thing or anything, really, for women in those days. That hasn't changed, unfortunately. You'd go to the support group at HIV Edmonton and it was 15 gay men and one or two women. It was really uncomfortable but I really wasn't interested in creating a support group. I was interested in finding women that I could talk to when I wanted to.

About a year or two later, HIV Edmonton started the Living Positive program for HIV positive people, where I worked as the executive director for nine years. We tried to stay close with HIV Edmonton; they were focused on prevention and we were focused on support. I was the first woman in Canada who was the executive director of a society for persons living with HIV.

My advocacy work revolves around the stigma against women with HIV. When people first hear me talk about it, their heads whip around and they stare. So many still believe this is a gay man's disease. I'm a middle-aged, straight woman who has never used intravenous drugs. I can't say that living with HIV is a normal life, because it's not. It's not. There is a whole pile of unanswered questions and there is no cure. Even if there was a cure, I'd still have to live through the isolation. I know how horrible it is to be alone without any support, thinking you're going to die, and with everyone around you thinking you're going to die too. It's been 18 years since I've been diagnosed, I've been positive for 25 years, and I ain't dying soon.

I'm doing much better, but I still need people to talk with and tell my story to. I know there will always be judgment and yes, I've done stupid things in my life and lots of things are my fault, but there are lots of things that aren't my fault. And I'm never going to change other people. But people have to start seeing there is always another side to the story.

I still feel good about helping women who are devastated like I was. An hour after talking with me, they're smiling, laughing and saying, "Oh, this isn't a big deal. It is a big deal, but it's not." This kind of dialogue needs to happen, and no one can do it except another positive person. And that's who I am. whether I want to be or not.

CHANTAL LONDJI DANG

Executive Director of the Madeleine Sanem Foundation that works with French-speaking African communities





DENISE LAMBERT

Executive Director of Kīnamow Atoskanow Foundation that works with Aboriginal communities


CHARLOTTE
MACKAY
Manager of Kairos House,
assisted living for people
who have HIV and AIDS



RICK MCHUTCHION

Former staff at the AIDS Division of Alberta, Consultant for the Non-Prescription Needle Use Consortium

MARLISS TAYLOR

Program Manager
Streetworks Needle Exchange,
Community Health Nurse



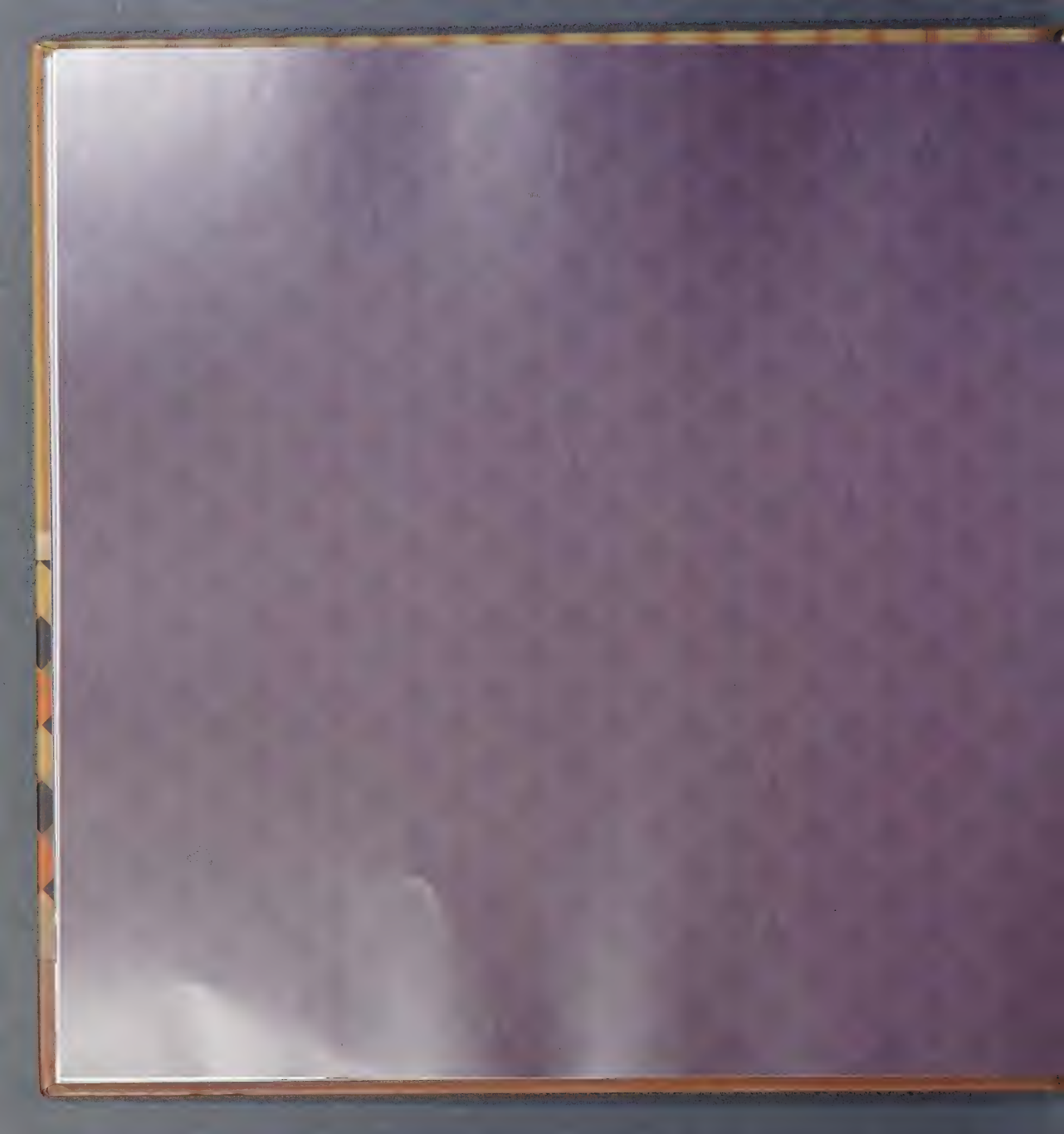


SHAWNA HOHENDORFF

Boyle McCauley Health Centre Programs: Kindred House

WENDI MONAHAN

Boyle McCauley Health Centre Programs: HAART House



07

Those Living with HIV and Telling Their Stories



KEN WARD

I'm surprised by the emotion I sometimes still feel when I tell my story. Enoch, Alberta was my home, but I became a ward of the government at the age of five and went to residential schools. At thirteen years old, while living in St. Paul, I was raped by an older man. After that, I was confused and lost about my sexuality. That's why I started doing drugs and drinking a lot. It's also when many of my suicide attempts occurred. When I was fifteen, I went to court and the judge sent me to Alberta Hospital to be assessed. That got me into a group home in Edmonton. That was my freedom.

I became ill in November, 1989 and was diagnosed as HIV positive four days after Christmas. I was a former drug addict and figured it had caught up to me. We didn't know much about HIV and AIDS back then. I was traumatized, shocked, and overwhelmed with fear. I took it as a death sentence. The first person I told was my older brother, Glenn. We used to drink together a lot and we were very close. We both cried, but we didn't hug each other, because I didn't know if I could pass it on. I was afraid and he was too. Then we told my mother and my older sister, Myrtle.

Two months after being diagnosed, the Alberta Indian Health Care Commission was organizing a rally about our treaty rights and health care benefits. It was my Mom who told me to attend, because of my sickness. She was worried about who would pay for my medications and treatment if our rights were taken away. My intention was just to go and support in a quiet way, as I didn't want people knowing about me. I didn't know that my mother had let the cat out of the bag and told the organizer about my HIV status.

Glenn offered to drive me, but I wanted to walk. He wore his cowboy hat and boots, and, being a drinker, had a big potbelly. He was mad about having to walk almost as soon as we started, but I felt pretty cocky about it, like I had a purpose.

As we got close to the rally, we could see that the media were there. They had heard the scoop about the first time in Canada an Indian would go public about his HIV diagnosis. When we arrived, a hush fell over



the crowd. I was then asked to say a few words. After standing there shuddering, I finally said, "My name is Ken Ward and I am from the Enoch Cree Nation...and I have HIV. I'm here to support our rights, but I'm also here to tell you that this disease is going to hit our people."

As soon as I said that, I wanted to cry so much. I looked over to the elders. Everyone was silent. Then, someone holding an eagle feather came up and handed it to me. The presentation of this feather was a powerful, symbolic act. It sent out the message: "We honour you because of the sacrifice you are making for our people. This is to give you courage and hope on your journey." I was used to having a glass syringe as my lover, my partner, but from that moment on, that eagle feather became my companion of hope.

I then realized that I needed to learn more about this disease. The AIDS Network invited me to become part of their family. They gave me an office space where I set up recruitment, and met with doctors and the Métis elders. There was a nice, small blend of people who were concerned. The AIDS Network became our home. We created The Feather of Hope Society, with the key mission of prevention and education.

I am a storyteller and a pioneer of this illness for our people. It has crafted me so that I may share other people's teachings: the humour, even in death, but also the darker side. In sharing their journeys, they become legacies. That's part of bringing dignity to the memory of their lives.

The disease has become more manageable now. Ten years ago, I thought the saddest thing I could ever see would be for our numbers to increase. Now, I'm still alive and the numbers are indeed going up. That's why I still struggle. I'm not perfect and I'm not strong. I prefer to be weak, but in a good way, because I choose to live a humble life. There are still times of discouragement when I just want to pack it all in and become a drunk. You see the inconsistencies, the ignorance, and the denial. Communities are still in denial about this disease.

I know my journey doesn't end here. I fulfill most of my goals by being a writer and a contributor. What keeps me going is that person out there who needs to feel like they aren't alone. I have to share my journey, including my pain, and I will talk to anybody who wants to listen. I've always stood on my own, but I'm grateful to all those who were stepping stones for me in my past. It took spirit of the heart back then and that continues to be a driving force of my existence. So if there is any legacy, I think it is in discovering that balance between different worlds, whether they be sexual identity, cultural-ethnic identities, or living with HIV.

Always remember that we are the last standing warriors.

JEFF KELLER

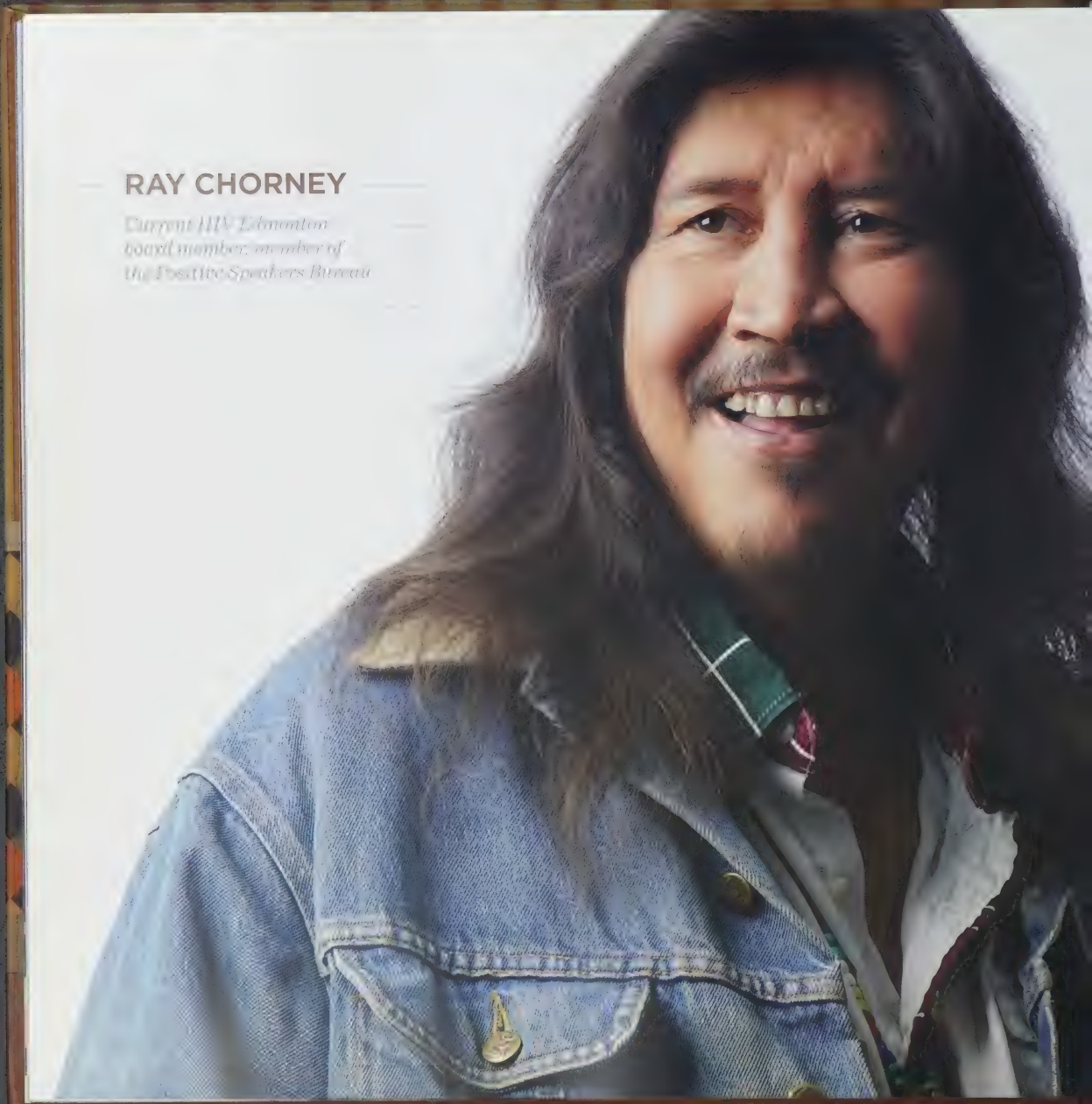
AIDS activist, former board chair of HIV Edmonton





CURTIS BRANSTON

Former Living Positive staff member of the Positive Speakers Bureau


RAY CHORNEY
Current HIV Edmonton
board member, member of
the Positive Speakers Bureau



08

Those Who Aren't Here to Tell Their Stories

For everyone we've lost to HIV and AIDS.

I REMEMBER ROSS ARMSTRONG

In 1981, my roommate Matthew urged me to join the Edmonton Roughnecks Volleyball Club. I spent many a pleasant weekend afternoon playing with the guys and one of them was Ross Armstrong. Ross was full of the playful spirit that either endeared him to you or annoyed you to the point of grimacing. I was newly out of my marriage and the secret and silent closet, so Ross intrigued me because he was so comfortable in his own skin and so open in expressing himself.

We heard a lot about a terrifying disease that was spreading through gay communities south of the border in those days. It was terrifying on at least two counts. One was that it seemed to be incurable and fatal, and the other was that no one seemed certain how it was spread. There were many rumours about how it was caught and one of them connected it to the use of amyl or butyl nitrate or poppers — the legal high of the time which was used medically as a cardiac stimulant in emergency situations but created a high rush in normal folks. It turned out to be a false rumour, but no one knew what actually did trigger the problems — and there were many of them.

Unfortunately, Ross came down with enough symptoms of opportunistic conditions to qualify for the diagnosis of having Auto Immune Disease or Deficiency Syndrome (AIDS) and was hospitalized in an isolation unit at the University of Alberta Hospital. Fortunately, that was where I worked as a director of media productions, so I could visit him as often as twice a day.

The health care providers were as scared as the rest of us and the precautions showed it. To enter Ross' room, you had to put on a gown and wear gloves and a mask. On one visit, I discovered that they had just placed his food inside the door, so I took it to him. Another time, I sat on the bed next to him and hugged him. It was the first physical contact he had received in days. I told him I was wearing all of the protective gear to prevent me from bringing anything into his space. He was dealing with more than enough already, so he didn't need anything that I might introduce into his almost sterile area.

Ross was the first public AIDS patient in Edmonton and certainly the first one I knew of. I was to get to know many more in the next decade. I was a minister with the Metropolitan Community Church of Edmonton (MCC-Edmonton) which ministered mainly to the GLBTQ folks who had been shunned by their faith communities. In that capacity, I was asked to conduct many memorial services for guys I knew and for those whose friends or family requested my services. I was grateful that I could provide some comfort to those who were experiencing such grief and sometimes such shock at discovering that their son was gay and also had AIDS.

Ross died, as did most of the early patients. For many years, the gay community and our comrades in arms, our lesbian sisters, reeled at the growing numbers of young men lost. We made quilts to remember them by. We marched. We held vigils to pray for the sufferers and the healthcare providers and all who held their hands and tried to support them.

In 1982, I met the sculptor Patrick Morin, my first husband. Although we had seven years together, he spent the last four living with AIDS. He spent the last year of his life in and out of the same University Hospital where I visited him morning, noon and night on days I was working. He finally died in February, 1989.

I am still HIV-negative by some quirk of nature and one of his HIV-positive buddies is still alive and healthy, thanks to the cocktail of anti-retroviral drugs that finally acted as a means to stop people from dying of HIV complications. Unfortunately, they came too late for Patrick.

In 1984, Michael Phair and several others in the gay community were so concerned with the lack of action on the part of the medical research community and the level of support for AIDS sufferers that they formed the AIDS Network of Edmonton and applied for funding. Since this group was so new, it had not yet achieved charitable status and was unable to receive the funds offered to them. Michael and I had become friends, so I asked the Board of MCC-Edmonton if they would receive the funds and use them to pay the expenses of the new AIDS Network. The Board agreed and the funds supported the initiatives of the Network in getting various agencies to cooperate and provide services to AIDS sufferers.

Margaret Mead, the anthropologist, said, "Never doubt that a small group of thoughtful citizens can change the world. Indeed, it is the only thing that ever has." Michael, and the others he gathered around his kitchen table, certainly proved that point in Edmonton.

The Reverend Charles M. Bidwell, *PhD.*
June 2010



AFTERWORD

The feat of capturing everyone that was involved and encapsulating everything that occurred in the Edmonton AIDS movement over the past 25 years is an impossible one. But what a history. In preparing for this book, we selected just a few of the incalculable key players to help tell our story. Because of the vast scope of the work, there are countless people with chapters to add and we will regrettably miss some who have changed the community.

In the early years, the words "AIDS" and "fear" were synonymous. The agency, then known as the AIDS Network of Edmonton, struggled to secure funding and office space. The gay and lesbian community were rapidly losing friends and loved ones to this disease and so provided the funds needed to dispel myths, promote education, and lessen panic. The agency's first fundraiser, Alice's Tea Party in Victoria Park, provided money to inform Edmontonians about AIDS. Over time, the city provided office space. While most people reacted with fear or indifference, thinking AIDS was not an issue in Edmonton, our founders were tireless in their efforts. Ross Armstrong, the first publicly disclosed case of AIDS in Edmonton, had the bravery and foresight to commit himself to reducing the stigma and shame associated with the disease. Our first Executive Director, Barry Breau, gave completely of himself and strove to make a difference in the lives of people with HIV and AIDS. Programs of the AIDS Network flourished and branched off to form new organizations, such as Living Positive. The network of people and organizations grew. For example, in the late eighties, Catholic Social Services opened Kairos House, with the mandate of helping people to die with dignity.

Most "well-aged" Edmontonians who were a part of the early epidemic lost several and some as many as forty friends, colleagues and/or loved ones. Our city's infectious disease doctors said goodbye to countless patients. Can you imagine the loss? As a native of Edmonton, reflecting on this loss makes the city feel empty.

But through advances in medicine and research, many of those involved have also found strength and optimism. One of my mentors, Bob Mills, died in 2003. His death was a loss to the local and national AIDS movement. Bob helped many people to see beyond all the death and to live with hope. He was passionate and will be forever remembered as an activist, treatment advocate, PHA and all-around bossy board member. In 2001, Bob was nominated by the Canadian AIDS Society and chosen by Minister Alan Rock as part of the Canadian Delegation of the UNGASS (United Nations General Assembly on HIV/AIDS). Canada was a key member in drafting the *Declaration of Commitment* and, while not a binding document, 189 countries worldwide signed the Declaration and report their progress on agreed upon targets in their attempts to stem the pandemic. While there is still much more to do, advancements have been made, treatment has improved, people are living longer, and an increasing number of people in the developing world are receiving treatment.

From humble beginnings as part of a grassroots movement, supported by physicians and members of the gay and lesbian community, AIDS work has come a long way in this city. The goal of our early founders to create a "network" of people and organizations passionately involved in AIDS work has come to fruition. HIV and AIDS is a part of the collective history of this city. Each day, when you stop to talk with someone on the street in Edmonton, does it ever cross your mind if HIV has affected them? Affected their family or friends? Maybe the person you stopped to speak to is HIV positive? While we have come a long way, being part of the HIV community is still not necessarily something a person will openly share with you on the street. Stigma and discrimination still exist. Sometimes, people still react negatively when I tell them where I work. While the disease is more manageable and the burden of living with HIV or working in the field has eased, it is not *easy*.

If we include Michael Phair's house, the office we have recently moved into is our eighth home in 25 years. In my decade of employment by HIV Edmonton, I have experienced three moves into new spaces because of lease non-renewal. Intolerance and stigma often make people, businesses, and other non-profit organizations feel we are inappropriate neighbours.

I have a sign on my office door. It reads – *Assume hope all who enter here.* As you finish reading this book and sharing in our history, that is the message I would like to leave you with. We are all part of the Legacy.

DEBRA JAKUBEC
HIV Edmonton Executive Director

December 1, 2010

GLOSSARY

Commmon terms used through the book:

AIDS Acronym for Acquired Immune Deficiency Syndrome, a syndrome caused by HIV (see definition below). HIV, which is transmitted from one individual to another through the exchange of bodily fluids (such as blood or semen), attacks white blood cells, thereby causing the body to lose its capacity to ward off infection. In Canada, AIDS is diagnosed if a person has:

1. Undergone testing for HIV and received a positive result, and
2. Has one or more of the clinical illnesses. or indicator diseases. that characterize AIDS.

Epidemiologist A scientist whose area of study focuses on the causes, distribution, and control of disease in populations.

HAART Acronym for Highly Active Anti-Retroviral Therapy.

HAART is the name given to aggressive treatment regimens used to suppress HIV viral replication and the progression of HIV. HAART regimens have proven to reduce the amount of active virus (or viral load) and in some cases can lower the viral load until it is undetectable by current blood testing techniques.

HIV Acronym for Human Immunodeficiency Virus, a virus that attacks the immune system, resulting in a chronic, progressive illness that leaves people vulnerable to opportunistic infections and cancers.

Incidence The number of new cases per population in a given time period. Incidence should not be confused with prevalence. (See definition below.)

Infectious Disease Any disease caused by invasion by a pathogen which subsequently grows and multiplies in the body. Also referred to as communicable diseases, infectious diseases include influenza, hepatitis, HPV, HIV and STIs. (See definition below.)

Lazarus Effect A phrase used to describe the impact of HAART on patients suffering from AIDS, referring to the parable recounted in the Gospel of John, in which Jesus restores Lazarus to life after being dead for four days. There have been examples of people who were quite close to death, starting treatment on the first AIDS drug AZT and making remarkable recoveries.

Methadone A synthetic opioid, used medically in the treatment of opioid dependence (heroin, morphine). Oral doses of methadone can stabilize patients by mitigating withdrawal syndrome. Higher doses of methadone can block the euphoric effects of heroin, morphine, and similar drugs. As a result, properly dosed methadone patients can reduce or stop altogether their use of these substances. It is not intended to reduce the use of non-narcotic drugs such as cocaine, methamphetamine, or alcohol.

In response to the increasing numbers of HIV infections among injection drug users and lack of methadone treatment available in Alberta, HIV Edmonton started a methadone clinic in 2003.

Palliative care Palliative care is care that improves the quality of life of patients and their families facing life-threatening illness. With palliative care particular attention is given to the prevention, assessment, and treatment of pain and other symptoms, and to the provision of psychological, spiritual and emotional support.

Pandemic A disease that spreads across an entire region, continent or the whole world. Preferred usage is to write pandemic when referring to global disease and to use epidemic when referring to country or regional level.

PHA Acronym for a Person who Has AIDS. Other common terms are PLWA (Person Living with AIDS) and PLWHA (Person Living with HIV and AIDS).

Prevalence The proportion of the total number of cases to total population. Prevalence should not be confused with incidence. (See definition above.)

Protease Inhibitor The class of anti-HIV drugs that interfere with the action of the HIV enzyme called protease. They prevent the protease enzyme from cutting the long chains of new HIV proteins. This results in defective virus that cannot infect new cells.

Retrovirus A virus composed not of DNA but of RNA. Retroviruses have an enzyme called reverse transcriptase that gives them the unique property of transcribing RNA (their RNA) into DNA. The retroviral DNA can then integrate into the chromosomal DNA of the host cell to be expressed there. The human immunodeficiency virus (HIV) is a retrovirus.

STI Acronym for Sexually Transmitted Infection, an infection that can be transferred from one person to another through sexual contact. In this context, sexual contact is more than just sexual intercourse (vaginal and anal) and also includes kissing, oral-genital contact, and the sharing of sexual toys, such as vibrators.

Among the sexually transmitted infections (STIs) are:

- Chlamydia
- Syphilis
- Genital warts, HPV
- Gonorrhea
- Genital herpes
- HIV/AIDS

The term sexually transmitted infection or STI corresponds to and is meant to replace the older term sexually transmitted disease or STD.

Partner organizations referred to in the book:

Boyle McCauley Health Centre Programs: HAART House
HAART House is a program that endeavors to improve medication compliance amongst inner city residents who have difficulty adhering to their anti-retroviral medication treatment regimens.

Boyle McCauley Health Centre Programs: Kindred House
Kindred House is a safe house and resource centre for women and transgendered individuals who are involved in street prostitution.

CAS or Canadian AIDS Society
The Canadian AIDS Society was created after the first Canadian AIDS Conference in Montreal in May of 1985. A steering group that included Kevin Orr from the AIDS Committee of Toronto, Michael Phair of the AIDS Network of Edmonton, and Richard Burzynski of AIDS Community Care Montreal, worked together to formalise the association.

Feather of Hope Society
Feather of Hope was an AIDS service organization that provided culturally appropriate programming specific to the Aboriginal community in Edmonton. This program closed in 2000.

Interfaith HIV/AIDS Program
Interfaith focused specifically on dealing with HIV and AIDS issues with faith-based organizations. This program no longer operates in Edmonton.

Kairos House
Kairos House is a program of Catholic Social Services and provides an assisted living home that offers housing to people living with HIV and AIDS. It was originally opened as a palliative care centre but has expanded its mandate since the advent of medication.

Kimamow Atoskanow Foundation
Translated from Cree into English, Kimamow Atoskanow means *"we all work together."* The Kimamow Atoskanow Foundation was incorporated in 1992 and provides HIV and AIDS support and education to Aboriginal Albertans.

Living Positive
Living Positive was created and run by people living with HIV. Living Positive advocates for people living with HIV in matters relating to HIV and provides peer support, public education and awareness services.

Madeleine Sanem Foundation
The Madeleine Sanem Foundation provides HIV related education and support to African community members in Edmonton. They focus more specifically on French-speaking communities.

Non-Prescription Needle Use Consortium
In 1994, the Provincial AIDS Program established the Non-Prescription Needle Use Project, which initiated a series of 3-year action plans based on the principles of the harm reduction and population health, and was overseen by a 30-plus member Consortium comprised of community, professional, and multi-level government representatives. It was terminated November of 2009.

Northern Alberta Clinic
The Northern Alberta Clinic provides care, treatment, and support to people living with HIV and AIDS. Clinics are available at both the University of Alberta and Royal Alexandra hospitals. The clinic provides services to all people living with HIV and AIDS from Red Deer to the north.

Provincial AIDS Program
The Provincial AIDS Program was a branch of Alberta Health and Wellness that dealt with prevention, treatment, care and support issues regarding HIV and AIDS. It provided expertise, direct services, funding and other and community support from 1990 to 2005.

Streetworks Needle Exchange
Streetworks began in 1989 as Needleworks, after 8 city agencies, including Alberta Health Services, Edmonton Police Service and the Medical Officer of Health, gathered to address the issue of HIV amongst injection drug users and sex trade workers. This program is governed by a council and has its main office at the Boyle Street Community Centre. Streetworks provides needle exchange, harm reduction education and resources, nursing services, and support to people who use injection drugs.

UNGASS
An acronym for the United Nations General Assembly Special Sessions. The first special session on HIV and AIDS was held in 2000.

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